

AMENDED IN SENATE MAY 1, 2012  
AMENDED IN SENATE MARCH 27, 2012

**SENATE BILL**

**No. 1267**

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**Introduced by Senator Padilla**

February 23, 2012

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An act to add Chapter 2.6 (commencing with Section 56.18) to Part 2.6 of Division 1 of the Civil Code, relating to genetic information.

LEGISLATIVE COUNSEL'S DIGEST

SB 1267, as amended, Padilla. Genetic Information Privacy Act.

Existing law prohibits discrimination on the basis of genetic information under various provisions of law, including, among others, the Unruh Civil Rights Act and the California Fair Employment and Housing Act. Existing law prohibits discrimination in the enrollment of health insurance plans on the basis of an individual's genetic characteristics, as defined. Existing law also imposes prohibitions on the disclosure by a health care service plan of the results of a test for a genetic characteristic contained in an applicant's or enrollee's medical records.

This bill would establish the Genetic Information Privacy Act, which would provide that an individual's genetic information, as defined, is protected by the right of privacy, *as specified*. The bill would, notwithstanding any other law, prohibit any person, as defined, from obtaining, analyzing, or disclosing genetic information without the written authorization of the individual to whom the information pertains, as specified, ~~and~~. ~~The bill would establish civil and criminal penalties for a violation of this prohibition, as specified. However, this~~ *The bill would require a separate written authorization for each separate disclosure of an individual's genetic information. The bill would also*

*provide a written authorization form to be used to obtain the written authorization described above.*

*This bill would exempt certain individuals from ~~these~~ the prohibitions and penalties described above, including, among others, law enforcement officials in the execution of their official duties, as specified, and hospitals, laboratories, and physicians carrying out court-ordered tests; ~~licensed health care professionals in medical emergencies, coroners and medical examiners in the execution of their official duties, any screening of newborn infants required by state or federal law, and.~~ The bill would permit disaggregated and anonymized data, as defined, that was ~~either~~ collected before the bill's enactment ~~or if written consent is obtained~~ to be used, as specified, without the authorization described above. The bill would also permit the use of disaggregated and anonymized data, as specified, if the written authorization described above is obtained and the data is used for a purpose authorized by the individual to whom the information pertains. By creating new crimes, the bill would impose a state-mandated local program.*

The California Constitution requires the state to reimburse local agencies and school districts for certain costs mandated by the state. Statutory provisions establish procedures for making that reimbursement.

This bill would provide that no reimbursement is required by this act because it creates new crimes.

Vote: majority. Appropriation: no. Fiscal committee: yes.  
State-mandated local program: yes.

*The people of the State of California do enact as follows:*

- 1     SECTION 1. Chapter 2.6 (commencing with Section 56.18)
- 2     is added to Part 2.6 of Division 1 of the Civil Code, to read:
- 3
- 4                     CHAPTER 2.6. GENETIC PRIVACY
- 5
- 6     56.18. (a) This chapter shall be known, and may be cited, as
- 7     the Genetic Information Privacy Act.
- 8     (b) For purposes of this chapter, the following definitions apply:
- 9     (1) "Anonymized" means data from which an individual's
- 10    identifying information has been removed.

1 (2) “DNA sample” means any human biological specimen that  
2 is obtained or retained for the purpose of extracting and analyzing  
3 DNA to perform a genetic test.

4 (3) “Genetic characteristic” includes a gene, chromosome, or  
5 alteration thereof that may be tested to determine the existence or  
6 risk of a disease, disorder, trait, propensity, or syndrome, or to  
7 identify an individual or a blood relative.

8 (4) “Genetic information” means, with respect to an individual,  
9 information ~~about~~ *obtained from* the genetic tests of the individual,  
10 the genetic tests of the individual’s family members, and the  
11 manifestation of a disease or disorder in family members of the  
12 individual. The term includes a request for, or receipt of, genetic  
13 services, or participation in clinical research that includes genetic  
14 services, by the individual or a family member of the individual.  
15 *Genetic information includes a DNA sample.*

16 (5) “Genetic service” means a genetic test, genetic education,  
17 or genetic counseling, including obtaining, interpreting, or  
18 assessing genetic information.

19 (6) “Genetic test” means a test for determining the presence or  
20 absence of genetic characteristics in an individual or the  
21 individual’s blood relatives, including tests of nucleic acids such  
22 as DNA, RNA, and mitochondrial DNA, chromosomes, or proteins  
23 in order to diagnose or determine a genetic characteristic.

24 (7) “Person” means an individual, partnership, corporation,  
25 association, business, business trust, or legal representative of an  
26 organization.

27 56.19. (a) Genetic information is protected by the right of  
28 privacy *pursuant to Article I of Section 1 of the California*  
29 *Constitution*, and, notwithstanding subdivision (c) of Section 56.10,  
30 or any other law, shall not be obtained, analyzed, retained, or  
31 disclosed without the written authorization of the individual *to*  
32 *whom the information pertains* pursuant to subdivision (g). *A*  
33 *separate written authorization is required for each separate*  
34 *disclosure of an individual’s genetic information.*

35 (b) Any person who negligently violates subdivision (a) shall  
36 be assessed a civil penalty in an amount not to exceed one thousand  
37 dollars (\$1,000) plus court costs, as determined by the court, which  
38 penalty and costs shall be paid to the individual to whom the  
39 genetic information pertains.

(c) Any person who willfully violates subdivision (a) shall be assessed a civil penalty in an amount not less than one thousand dollars (\$1,000) and not more than five thousand dollars (\$5,000) plus court costs, as determined by the court, which penalty and costs shall be paid to the individual to whom the genetic information pertains.

(d) Any person who willfully or negligently violates subdivision (a) and the violation results in economic, bodily, or emotional harm to the individual to whom the genetic information pertains, is guilty of a misdemeanor punishable by a fine not to exceed ten thousand dollars (\$10,000).

(e) In addition to the penalties listed in subdivisions (b) and (c), a person who commits an act described in subdivision (b) or (c) shall be liable to the person to whom the genetic information pertains for all actual damages, including damages for economic, bodily, or emotional harm which is proximately caused by the act.

(f) Each violation of this section is a separate and actionable offense.

(g) (1) The written authorization required by this section shall satisfy all of the following requirements:

~~(1) Is~~

(A) *The written authorization shall be written in plain language and is be* in a typeface no smaller than 14-point type.

~~(2) Is~~

(B) *The written authorization shall be dated and signed by the individual to whom the information pertains or a person authorized to act on behalf of the individual.*

~~(3) Specifies the types of persons authorized to obtain, analyze, or disclose genetic information about the individual.~~

~~(4) Specifies the nature of the genetic information authorized to be obtained, analyzed, or disclosed.~~

~~(5) States the name or functions of the persons or entities authorized to obtain, analyze, or receive the information.~~

~~(6) Specifies the purposes for which the information is collected.~~

~~(7) Specifies the length of time the authorization shall remain valid.~~

~~(8) Specifies whether the genetic information may be used for any commercial purpose.~~

~~(9) Specifies whether the genetic information shall remain identifiable or shall be made nonidentifiable.~~

~~(10) If the information is retained, specifies the manner in which the information shall be stored.~~

~~(11) Requires the destruction of the genetic information and sample after the specific purpose for which the consent was granted has been fulfilled.~~

~~(12) Permits the individual to limit access to the information to a certain person or persons.~~

~~(13) Permits the individual to revoke his or her consent in writing at any time.~~

~~(14) Advises the individual signing the authorization of the right to receive a copy of the authorization. Written authorization is required for each separate disclosure of the genetic information.~~

~~(h) This section shall not apply to the following:~~

~~(C) The written authorization shall be a separate document, not attached to any other document, and shall not be more than one page.~~

~~(2) Any person who obtains, analyzes, retains, or discloses the genetic information of an individual shall use the following written form to obtain the authorization of the individual to whom the information pertains as required by subdivision (a) so that the individual may make a decision and provide direction regarding the use of his or her genetic information:~~

*Important Privacy Choices*

*You have the right to control the use of your genetic information that you give to us. Please read the following information carefully before you make your choices below.*

*Important Information Regarding Your Genetic Information:*

• *The following types of people are authorized to obtain, analyze, retain, or disclose your genetic information: \_\_\_\_\_*

• *The following is the nature of the genetic information that you are authorizing to be obtained, analyzed, retained, or disclosed:*

• *The following is the name of the person(s) authorized to obtain, analyze, retain, or disclose your genetic information and his or her function: \_\_\_\_\_*

• *Your genetic information is being collected for the following purpose: \_\_\_\_\_*

*Unless you say otherwise as indicated below, your genetic information may not be used for any other purpose.*

- 1     • *This authorization shall remain valid for as long as it takes to*  
2     *carry out the purpose indicated above.*  
3     • *The genetic information you give us will remain (\_\_\_\_)*  
4     *identifiable or (\_\_\_\_) will be made nonidentifiable.*  
5     • *If we retain your genetic information, the following is the*  
6     *manner in which it will be stored:\_\_\_\_\_*

7  
8     *Your Rights Regarding Your Genetic Information:*

- 9     • *You have the right to limit the purposes for which your genetic*  
10    *information is used.*  
11    • *Once we fulfill the purpose(s) you have authorized in this form,*  
12    *we are required by law to destroy the genetic information and*  
13    *sample that you provide us.*  
14    • *You are permitted to limit access to your genetic information*  
15    *to a certain person or persons.*  
16    • *You are permitted to revoke this authorization at any time.*  
17    • *You have a right to a copy of this authorization.*

18  
19    *Your Choices Regarding Your Genetic Information:*

- 20    (☐) *In addition to the purpose noted above, I authorize my*  
21    *genetic information to be used for research purposes.*  
22    (☐) *In addition to the purpose noted above, I authorize my*  
23    *genetic information to be used for commercial purposes.*  
24    (☐) *I would like to limit the purpose for which my genetic*  
25    *information is authorized to be used in the following*  
26    *way:\_\_\_\_\_*  
27    (☐) *I would like to limit access to my genetic information to the*  
28    *following person or persons:\_\_\_\_\_*  
29    (☐) *I would like to receive a copy of this authorization.*  
30    (☐) *I would like to revoke this authorization.*

31  
32    (h) *Any person who obtains, analyzes, retains, or discloses the*  
33    *genetic information of an individual shall comply with the*  
34    *following:*

- 35    (1) *The person may not obtain, analyze, retain, or disclose the*  
36    *genetic information for any purpose other than the purpose*  
37    *authorized by the individual to whom the information pertains.*  
38    (2) *Once the specific purpose authorized by the individual to*  
39    *whom the genetic information pertains has been fulfilled, the*

1 individual's genetic information and DNA sample shall be  
2 destroyed.

3 (3) The person shall permit an individual to limit access to his  
4 or her genetic information to a certain person or persons.

5 (4) The person shall permit an individual to revoke an  
6 authorization signed pursuant to subdivision (g) at any time.

7 (5) The person shall provide an individual who has signed an  
8 authorization pursuant to subdivision (g) with a copy of that  
9 authorization upon request.

10  
11 (i) Genetic information may be obtained, analyzed, retained,  
12 or disclosed without the authorization provided in subdivision (g)  
13 in the following instances provided that the entity may obtain,  
14 analyze, retain, or disclose the information only for the specified  
15 purposes indicated, and any use for any other purpose is subject  
16 to the authorization required in subdivision (a):

17 (1) A law enforcement official in the execution of his or her  
18 official duties consistent with existing law.

19 (2) A hospital, laboratory, or physician carrying out  
20 court-ordered tests for genetic information.

21 (3) A licensed health care professional, as defined in Section  
22 56.05, in medical emergencies.

23 (4) A coroner or medical examiner in the execution of his or  
24 her official duties consistent with existing law.

25 ~~(5) Disaggregated and anonymized data that was collected before~~  
26 ~~the enactment of the act adding this section.~~

27 ~~(6)~~

28 (5) Any screening of newborn infants required by state or federal  
29 law.

30 ~~(7) Disaggregated and anonymized data if written consent under~~  
31 ~~subdivision (g) is obtained.~~

32 (j) Disaggregated and anonymized data that was collected  
33 before the enactment of the act adding this section may be obtained,  
34 analyzed, retained, or disclosed without the authorization provided  
35 in subdivision (g).

36 (k) Disaggregated and anonymized data may be obtained,  
37 analyzed, retained, or disclosed if written authorization under  
38 subdivision (g) is obtained and the data is used for a purpose  
39 authorized by the individual to whom the information pertains.

1 SEC. 2. No reimbursement is required by this act pursuant to  
2 Section 6 of Article XIII B of the California Constitution because  
3 the only costs that may be incurred by a local agency or school  
4 district will be incurred because this act creates a new crime or  
5 infraction, eliminates a crime or infraction, or changes the penalty  
6 for a crime or infraction, within the meaning of Section 17556 of  
7 the Government Code, or changes the definition of a crime within  
8 the meaning of Section 6 of Article XIII B of the California  
9 Constitution.

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